

	<p>CHILD AND YOUTH MORTALITY REVIEW COMMITTEE</p> <p>Te Rōpū Arotake Auau Mate o te Hunga Tamariki, Taiohi</p> <p>Meeting Minutes Thursday 12 and Friday 13 February 2009 9.00 am to 5.00 pm</p>
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In Attendance:	Nick Baker (NB), Russell Franklin (RF), Chris Morris (CM), Eru George (EG), Anganette Hall (AH), Barry Taylor (BT), Liz Craig (LC), Marie Connolly (MC), Amanda d'Souza (AD) part meeting.
Apologies:	Riana Manual (RM)
Guests:	Glenys Needs (GN), Gabrielle McDonald (GM)
Secretariat:	Shelley Hanifan (SH), D Suzi Grindell (DSG), Terry Sarten (TS), Bruce Anderson (BA) part meeting, Aphra Green (AG) part meeting, Emalene Pearson (EP) part meeting, Annisha Vasutavan (AV) part meeting.

Agenda Items:	Summary of Discussions and Decisions
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CYMRC Meeting – Thursday 12 February 2009	
Opening	Meeting opened 9.15 am with a karakia.
Apologies	Action: Secretariat to check contact details for Riana Manual.
Previous minutes	Moved: Accepted as a true and correct record Taylor/George All agreed
Correspondence inwards	Inwards letters from Ministry of Health and Ministry of Consumer Affairs noted.
Correspondence outwards	Outwards letters to Ministry of Health and ACC were noted. Response from ACC supporting Dr John Wren becoming an advisor to CYMRC.
Correspondence tabled	Further correspondence was tabled at the meeting. a. From Vicki Culling, Sands NZ Inc, undated, to Chair about Sands support packs and offer to attend meeting to discuss. Noted that: <ul style="list-style-type: none"> • SANDS being approached to support families after SUDI this requires a different approach to still birth and neonatal death. The role of SIDS NZ needs to be clarified. • CYMRC SUDI working group is focused on prevention. Once this is covered focus can move to consider after-

	<p>care.</p> <p>Action:</p> <ol style="list-style-type: none"> i. Secretariat to find out what resources ACC can offer and SIDSNZ has the capacity to do. ii. Chair to respond to V Culling's letter and invite SANDS to advise next CYMRC meeting. <p>b. To Registrar-General, Births Deaths and Marriages, 5 February 2009. Request for specific data on behalf of CYMRC and PMMRC.</p> <p>Noted that</p> <ul style="list-style-type: none"> • the Registrar-General had disagreed with a Ministry of Health legal opinion and this was a response letter. • also that a follow-up letter was required as the full set of data needed had not been included in the request. • issues need to be sorted urgently as risk to CYMRC and LCYMRG process if information flow stops. <p>Action:</p> <ol style="list-style-type: none"> i. GN to email Secretariat a complete list of data required. ii. Secretariat to obtain further legal advice (Crown Law opinion) and resolve blocks to information flow. <p>c. Letter to Wanganui Chronicle in regard to M Laws's statement on mothers sleeping with children (Secretariat's email 5 February 2009).</p> <p>Moved: In future, when this issue (mothers sleeping with children) is raised, the letter will be used as the standard media response.</p> <p style="text-align: right;">Chair All agreed</p>
Action points from last meeting	See separate table for list of action points and progress.
Administration	<p>The Chair noted difficulties arising from frequent changes in staff within the Secretariat.</p> <p>The Secretariat requested CYMRC members to:</p> <ol style="list-style-type: none"> a. submit fee claims after every meeting and not leave until the end of the financial year. b. ensure travel bookings are made through the Ministry of Health's travel agents. <p>The Secretariat also explained why members will be asked to respond to a letter requesting a Declaration of Interests that is to be sent out before the next meeting.</p>

<p>CYMRC membership</p>	<p>The Chair noted that CM had signalled his intention to resign. Noted that:</p> <ul style="list-style-type: none"> • three vacancies puts CYMRC at risk of being inquorate during meetings although the Minister's appointment group has already advertised to replace Annie Bermingham (resigned) and Barry Taylor (expired) • CYMRC wishes to maintain balance between clinical and non-clinical membership important the Minister is aware of current members in selecting new ones. • A further request for nominations has recently been circulated by the MOH, the MOH currently holds names from previous request NOV 2007. <p>Action:</p> <ol style="list-style-type: none"> i. CM to formally inform the Minister of his resignation. ii. Secretariat is to clarify what is happening with nominations received to restore full membership.
<p>Impact of gobal financial crisis on CYMRC plans</p>	<p>A major change has occurred in the global economy requiring even more prudent use of every resource. The current government has not agreed to the CYMRC work plan and is in the process of reviewing all health expenditure. CYMRC discussed elements of previous work plan ensuring they were still needed and added value.</p> <p>The work plan had recognised the value of the vast amount of data now available for analysis and signalled a focus beyond collecting information to analysing data to create information that can be used catalyse change. It was felt important to communicate with the new Minister and develop a short briefing paper explaining the role of the Committee (<i>discussed further later</i>).</p> <p>Action:</p> <ol style="list-style-type: none"> i The Secretariat to provide: <ol style="list-style-type: none"> i.i a paper to the Chair on CYMRC spending during the last year and this financial year; figures to be broken down into activity groups such as local group, meetings, etc where possible i.ii Members with relevant sections of the government policy document i.iii support for CYMRC to continue with elements of work plan in process. ii The Chair will correspond with members by email to draft a briefing paper. <p>Conflict of Interest: In discussing the above, noted that BT has a conflict with his role in the Mortality Database Group, Otago University.</p>

<p>Scientific subgroup report</p>	<p>The subgroup had teleconferenced early February and met on 11 February. Noted that:</p> <ul style="list-style-type: none"> • in-depth reviews of particular topics were needed and resources required were approved in the CYMRC work plan but are not available for use until the current review of MOH spending is advanced. • the role of the Data Group in analysis needs to be clarified in contracting • any overlaps in work with NZHIS need to be defined to avoid duplication • while the ability of researchers to access the CYMRC data remains unclear progress is not being made in using these outside resources - research policy will be a standard agenda item • suicide researchers have still not been given a clear answer about ability to access data. <p>Agreed Action: Secretariat to work with subgroup to:</p> <ul style="list-style-type: none"> • develop a good example to illustrate the benefits from analysis of data to be included as an appendix to the briefing papers – Drowning • finalise a workable policy for mortality review committees to allow working with researchers when this can add value • with Data Group and NZHIS process needs speed up data sharing and make best use of coding. <p>Agreed: To explore addition of NZHIS coding into CYMRC database.</p> <p>Action:</p> <ol style="list-style-type: none"> i. AD would be an excellent new MOH member for Scientific Group but is to be confirmed. ii. Secretariat to ensure Constance Leman (MOH) is cc'd in on subgroup matters.
<p>Lead Coordinators report</p>	<p>TS tabled his report and noted:</p> <ul style="list-style-type: none"> • there are 10 functioning groups, TS has met with all existing groups • all other DHBs are making progress to have groups with 9 new chairs in place • very good joint working across the 3 Auckland DHB with strong clinical buy in to develop sharing of some case types. • the May local coordinators workshop is in preparation and an October workshop is planned as so many new groups will be in place • TS is based within the Whanganui DHB with an office and resourcing.

	<ul style="list-style-type: none"> • its is helpful to have regular teleconference contact between coordinators • feedback on draft hand book is being reviewed. <p>TS's focus is on improving connections between the local groups and CYMRC; local groups are very multi-disciplinary and look to CYMRC to reflect the multi-disciplinary approach not just a focus on the Health Sector.</p> <p>Quickplace has been non functional for some weeks forcing local groups to use other means of confidential communication. Advice has been provided that the names of the dead are public domain so these can be circulated on e-mail but no confidential information can be exchanged in this way. Even when working Quickplace is inaccessible to many for technical reasons that have not been resolved.</p> <p>Action: Secretariat to gain clarity around Quickplace issues and to work with Mortality Database group on resources for a secure system for information sharing that is accessible to LCYMG members.</p> <p>Action: TS to include a summary of the main issues/recommendations from local groups in future reports.</p>
<p>Ratification of appointments of chairs</p>	<p>Correction: Change Alice Leversha to Alison Leversha.</p> <p>Moved: that the recommendation that the Committee agree to ratify the appointment of the Chairs to the Auckland, Counties Manukau, Sth Canterbury, Waitemata and West Coast local committees previous agreed by the Chair, be accepted.</p> <p style="text-align: right;">Chair All agreed</p> <p>Action: Chairs and nominating DHBs are informed of this decision.</p> <p>Moved: that the recommendation that the Committee agree to ratify the reappointment of the chairs for Mid-Central, Tairawhiti and Taranaki to their local committees as previously agreed by the Chair.</p> <p style="text-align: right;">Chair All agreed</p> <p>Action: Chairs and nominating DHBs are informed of this decision.</p>
<p>Access of researchers to CYMRC information</p>	<p>SH tabled the draft paper 'Policy and procedure for the use of mortality review committee data in research' and that the paper</p>

	<p>had yet to go to Ministry of Health's legal advisors.</p> <p>Considerable discussion ensued including :</p> <ul style="list-style-type: none"> • the statement 'which will not be unreasonably withheld' could be added • researcher(s) must acknowledge use of data and source • should use comply with authorship criteria • conditions of use must include; no publication will contain identifiable data • should there be a test of relevance? • if researchers reuse data, will the original (local) provider still want to provide data to CYMRC? <p>Action:</p> <ol style="list-style-type: none"> i. CYMRC members to email SH their comments on the paper. ii. Secretariat to redraft the policy and procedure, and bring to the next meeting.
<p>When is Ethics committee approval needed?</p>	<p>GM tabled the paper 'Observational Studies and Ethics Committee Review, December 2006, National Ethics Advisory Committee'.</p> <p>Nearly all CYMRC studies are either 'observational' or 'quality assurance activities'. CYMRC does not need ethical approval to carry out studies for its statutory functions.</p> <p>Any CYMRC work, e.g. with the data from the Mortality Database, would be approved on a case by case basis. There may be benefit in obtaining a high level ethics committee approval for broad areas of work.</p> <p>Guidance will be in 'Policy and procedure for the use of mortality review committee data in research' being drafted by the Secretariat.</p> <p>Action: Secretariat continue to work on policy.</p>
<p>Drowning section for 5th report and plans for future work around drowning</p>	<p>The Chair presented the drowning section by Power Point presentation. (Presentation is confidential) There was considerable discussion particularly on the tables and the years to be covered. For trend data all CYMRC data will be used for analysis of current nature of a problem the last 5 years of CYMRC data will be used.</p> <p>Noted the messages coming from the research are:</p> <ul style="list-style-type: none"> • young children cannot be left alone at all near water • adult, not sibling, supervision is required always • some disabilities may increase risk

	<ul style="list-style-type: none"> • some community messages have been drafted for section 9 of the 5th report as a result. <p>Noted that Plunket has changed its Well Child strategy to include bath safety messages and the Well Child booklet now has a section on drowning.</p> <p>If the brief (see item Impact of global financial crises on CYMRC plans) for the Minister is to include examples, one might be drowning. An executive summary is needed and the tables should be at the back, possibly as appendices.</p> <p>Discussion on 5th report</p> <p>Agreed The 5th report will not be published until late 2009 and tables to include 2008 data with clear statements where this may be misleading e.g. where awaiting coroner may distort</p> <p>Action:</p> <ol style="list-style-type: none"> i NB to work with GN to get data consistent with regard to pool drowning. ii GM to review draft section on drowning ensuring any epilepsy messages are consistent. iii Secretariat to arrange with Consumer Affairs to undertake public education on baby bath seats.
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CYMRC Meeting – Friday 13 February 2009

In Attendance:	Nick Baker (NB), Russell Franklin (RF), Chris Morris (CM), Eru George (EG) part meeting, Anganette Hall (AH), Barry Taylor (BT), Liz Craig (LC), Marie Connolly (MC), Amanda d'Souza (AD) part meeting.
Apologies:	Riana Manual.
Guests:	Glenys Needs (GN), Gabrielle McDonald (GM) Part meeting.
Secretariat:	Terry Sarten (TS), D Suzi Grindell (DSG), Shelley Hanifan (SH) part meeting.

Karakia													
Continuation of discussion previous day on report	<p>Revised time line for CYMRC reporting is:-</p> <table border="1" style="width: 100%;"> <tr> <td>4th Report</td> <td>2002- 05</td> <td>Nov 2008</td> </tr> <tr> <td></td> <td>2002-07</td> <td>Briefing March 2009</td> </tr> <tr> <td>5th Report</td> <td>2002-08</td> <td>Nov 2009</td> </tr> <tr> <td>6th Report</td> <td>2002-09</td> <td>Nov 2010</td> </tr> </table> <p>After a lengthy discussion on what CYMRC needs to do for its 5th report and to achieve its 2008-09 work plan CYMRC concurred</p>	4 th Report	2002- 05	Nov 2008		2002-07	Briefing March 2009	5 th Report	2002-08	Nov 2009	6 th Report	2002-09	Nov 2010
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	<p>on the format of a briefing paper for the Minister; those who would draft each part identified, and the pathway forward that CYMRC would recommend to the Minister as the basis of the 2009-10 workplan.</p>
<p>Report from the SUDI working group.</p>	<p>The SUDI working group met on Wednesday, 11 February 2009. The Chair tabled the paper 'SUDI Issues Facts Messages and Enablers of Safe Environments'.</p> <p>The Chair noted that the Second National SUDI workshop was no longer being planned for this year. A theme emerging from the Working Group was that the members could use their own networks to share agreed messages and action. The working group would again meet again in April. The role of CYMRC is to support collaboration across the sector (Māori SIDS, Māori Women's Welfare League, La Leche League, NZ College of Midwives, Plunket, MOH divisions, Paediatric Society,) to get change.</p> <p>A strong theme from the workshop was a desire to form a Maori caucus to develop the best ways of enabling change for Maori.</p> <p>Moved: As a committee, CYMRC support the gathering of a Māori caucus to meet to advise the best way CYMRC and its SUDI working group can support Māori in reducing SUDI.</p> <p style="text-align: right;">AH/BT All agreed</p> <p>Action: EG (and possibly RM) to work with working group members to form a Maori caucus and to include others as needed. The first meeting could be for half a day on the 22nd April preceding the next working group meeting.</p> <p>Action: The Secretariat to support this action and involve other parts of MOH.</p> <p>Within the SUDI working group, there was agreement on most facts and principles but within detailed messages the level of agreement was less clear or there was disagreement in some areas. Exactly which enablers of change will be most effective was also unclear.</p> <p>The Chair then tabled the paper 'Shared commitment to SUDI prevention' (a declaration of organisational commitment). CYMRC members noted:</p> <ul style="list-style-type: none"> • could get resistance from organisations, although may get individuals to sign, organisational buy is vital if their networks are to spread consistent messages • if the working group is to have only two meetings this year then work to get buy-in needs to be by email • CYMRC focus is around providing a framework for the

	<p>many autonomous organisations to work together for change</p> <ul style="list-style-type: none"> • a professional training package may be required to take around NZ to midwives and well child providers. <p>Action Secretariat to circulate draft with SUDI workgroup Minutes and seek responses.</p>
<p>5th CYMRC report</p>	<p>The Chair reviewed the contents page. At the last meeting sections had been assigned to members. Members then revisited each section's coverage.</p> <p>Action:</p> <ol style="list-style-type: none"> TH to replace GN for the Recommendations section. NB to follow up with the NZ Transport Agency (formerly LTSA) around licensing of drivers re risk taking behaviour. TS on visits to CYMR local groups, to request the groups to look at after-care death pathways, for example provide a means for a GP to learn of a death rather than read it in the public notices of a newspaper. Change section (D) to 'Preventable Medical Deaths: i Asthma issues, ii Epilepsy, iii Diabetes' but leave until 6th Report. GM - appendices to be set as has been done in the past. <p>Moved: That CYMRC recommend to CYMR local groups that they develop 'after-care' pathways.</p> <p style="text-align: right;">Chair All agreed</p> <p>Action: TS to share drafts between Groups and generally facilitate the process.</p> <p>Noted that:</p> <ul style="list-style-type: none"> • Simon Denny had been contracted to write an editorial on risk-taking behaviour • Gabrielle McDonald is working as an agent on analysis of drowning data • CYMRC is generally happy with progress and content of the 5th report.
<p>Suicide Cluster report</p>	<p>BT discussed his report 'Review of a Cluster of Adolescent death from Self Harm, 2006, Otago, NZ'.</p> <p>It was the community that identified the cluster initially, with six deaths in six months of adolescents 15-18 years old. The report identified some trends, factors etc leading to death and the positive response to findings.</p>

	<p>A large number of recommendations arose from the study. These need to be checked that they are widely applicable and should form the basis of a wider discussion at next meeting.</p> <p>Action: Secretariat develop agenda for next meeting with time for suicide related discussion inviting MOH mental health advisor, MOH suicide project team leader and possibly others to this session.</p> <p>Action: BT and AH to work together on section on suicide for 5th report and a shorter summary for the briefing.</p>
<p>Access mortality review committee data</p>	<p>Secretariat tabled paper 'Flowchart of processes required for researcher so access mortality review committee data'.</p> <p>Wide discussion followed:</p> <ul style="list-style-type: none"> ▪ It is a difficult process even with a condition for CYMRC to have the final report as researchers still want to claim the information as their own. ▪ If the publication is of a poor standard, could CYMRC stop publication? ▪ There would have to be a formal application process which amongst other things would need to show relevance to CYMRC's objectives. ▪ CYMRC to date has not routinely encouraged access by external researchers but under special circumstance and special conditions, access might be granted. However where data can be obtained from other sources the other source should be used. ▪ "Internal" researchers should have a simplified access process. ▪ Identifiers within data would need to be removed before use and all costs associated with removal should be paid for by the researcher. ▪ Need to explore using Quickplace as a means of making data available but not to allow downloading. ▪ Processes would need to address cultural issues. <p>Any CYMRC process must be agreed to completely by the other mortality review committees before it could become operative.</p> <p>Action: Secretariat to liaise with Ethics Committees and with Chair PMMRC to identify criteria for access, conditions on access, indemnification of committee, etc, then approach PMMRC Chair for approval-in-principle, then to draft a procedures paper for next meeting.</p>
<p>Mortality review committees current</p>	<p>The three active committees are Family Violence Death Review Committee, Perinatal and Maternal Mortality Review Committee</p>

<p>position</p>	<p>and the Child and Youth Mortality Review Committee. The inactive committee is National Perioperative Mortality Review Committee.</p> <p>Noted that some monies allocated to these committees to carry out each committee's work plan is currently frozen while a review occurs. Money already contracted out is not effected by the freeze.</p> <p>Members requested a list of dates of appointment of all members.</p> <p>Action: Secretariat to obtain a list of dates of appointment of CYMRC committee members.</p>
<p>Other business</p>	
<p>1. Correspondence from Children's' Commissioner</p>	<p>The Chair had forward the correspondence to members prior to the meeting.</p> <p>The Chair's response will explain the local group process and that by next year there should be a local group for every DHB.</p> <p>Currently, CYMRC is not aware of any third party that has not performed as expected.</p> <p>Action: Chair to draft letter.</p>
<p>2. Government's manifesto</p>	<p>Secretariat tabled 'Better, Sooner, More Convenient: A summary of proposals, 26 September 2007, from the National Party'.</p> <p>CYMRC noted that most current directions are already closely aligned to this work. The major element being the clinically lead local review process that builds networks and provides opportunities for health gain, efficiency and improved quality and has an instant pathway to action change. CYMRC felt that the current format of it's Report did not adequately highlight the benefits of this work. The planned format for the 5th report will be better but the LCYMRC process needs to be given a higher profile as total national coverage occurs.</p> <p>Action:</p> <ol style="list-style-type: none"> i. Members to consider the draft brief when it is ready, and advise the Chair on what might be added or removed. ii. MC to suggest a few words around 'internationally seen as an exciting model'. iii. Three examples to be given: <ul style="list-style-type: none"> ▪ Suicide – BT and AH ▪ SUDI – LC and AT ▪ Drowning – NB GM and GN. iv. MOH to suggest to the Minister's office that the Minister

	<p>have a meeting with Chairs of all the mortality review committees to discuss common issues.</p> <p>v. CYMRC to request own meeting with Minister so age group specific issues can be highlighted.</p> <p>vi. All the above actions should be completed as soon possible.</p>
Meeting concluded at 4.00pm	
Next Meeting:	Thursday 23 and Friday 24 April 2009 at the Holiday Inn, Wellington, SUDI Working Group 22 nd April 2009, venue to be identified.

See separate paper for table of action items